

Musa Mayer



Contact Info:

Phone: [REDACTED]

Fax: [REDACTED]

Email: [REDACTED]

Educational Background:

B.A. Fine Arts New York University / Washington Square College, 1965

M.S. in Mental Health Counseling, Wright State University, Dayton, Ohio, 1976

M.F.A. in Writing, School of the Arts, Columbia University, New York, 1989.

Project Lead Training, National Breast Cancer Coalition, 1999

Project LEAD is an intensive science training program with a focus on cell biology and epidemiology initiated by NBCC to empower breast cancer advocates to serve as educated patient voices in a variety of venues where decisions are made about cancer research and public policy.

Advanced Project LEAD Training in Clinical Trials, 2001

Intensive training in all aspects of clinical trials design, monitoring and safety, as well as developing skills in the evaluation of clinical research.

Quality Care Project LEAD Training, 2006

Ongoing attendance at numerous medical and scientific conferences each year, including the San Antonio Breast Cancer Symposium, American Association for Cancer Research annual meetings, Department of Defense Breast Cancer Research Program *Era of Hope* conferences, American Society of Clinical Oncology annual meeting, National Comprehensive Cancer Network trainings, Cochrane Collaboration meetings, Chemotherapy Foundation Symposia, etc.

Relevant Employment:

1970-80 Counselor, Clinical Director, and Statistician, Ohio Community Mental Health System, with particular focus on leading groups, women's and family issues
(Employers: Antioch College, Encounter Programs, Good Samaritan Hospital Learning Center).

1986-2003 Free-lance journalist and author (see Publications)

1997-2003 Contributing Editor, MAMM Magazine: Women, Cancer and Community

2001-2004 Patient Representative/Consultant, FDA (see Advocacy)

2005-2007 Consultant to Living Beyond Breast Cancer (see Advocacy)

2005-2007 Consultant to U.S. Cochrane Center (see Teaching Experience)

2006-2007 Advocate, Center of Excellence (COE) Congressionally Directed Medical Research Program, Department of Defense (see Advocacy).

Teaching Experience

- 2007 Advocate Mentor Project LEAD.** Helped with training advocates in molecular biology, epidemiology, advocacy efforts in the National Breast Cancer Coalition's science training course.
- 2005-2007 Developer, *Understanding Evidence-Based Healthcare: A Foundation for Action*,** a web course for advocates, with Kay Dickersin, Director of the U.S. Cochrane Center, Johns Hopkins School of Public Health. A series of six publicly accessible training modules. Launched September 11, 2007 <http://cochrane.us>
- 2007 Advocate Mentor, Scientist ↔ Survivor Program,** American Association for Cancer Research annual conference, April 2007. Slide presentation: "How to Navigate the Annual Meeting."
- 2005 Teleconference presentation for Y-ME Volunteers, ASCO Update,** July 6, 2005
- 2005, 2006 Advocate Faculty, Accelerating Anticancer Agent Development and Validation Workshop,** jointly sponsored by AACR, FDA, ASCO, NCI and Duke University for drug developers. June 1-3 2005 Bethesda, MD
- 2003, 2006 Faculty, Clinical Trials Project LEAD.** One of two advocates who helped to train less experienced advocates on clinical trials and the drug development process. Taught workshops in advocacy issues in Phase II and Phase III trial design, early access to investigational drugs. I designed and led the "Navigating to Knowledge" workshop, which taught advocates how to use the Internet to keep up to date with breast cancer research.
- 2005 Teleconference and slide presentation** for FDA Office of Special Health Issues: "Serving as a Patient Representative on an FDA Advisory Committee." This slide presentation was for the purposes of training advocates who had recently become patient representatives in the FDA program about my four years experience with serving on the Oncologic Drugs Advisory Committee.
- 1994-2007 Vermont Studio Center Writing Program Faculty, Non-Fiction and Memoir**
- 1994-2002 Leader/Facilitator, Writing Our Way Home: The Power of Illness Narratives.** Day-long and weekend writing workshops for people with life-threatening illnesses, family and caregivers, and health professionals. Workshops have been sponsored by: Santa Barbara Community College; Breast Cancer Action of San Francisco; Y-Me Bay Area, San Jose; The Wellness Community, Philadelphia; Post-Treatment Resources Center at Sloan-Kettering Memorial Cancer Center, New York; The Breast Cancer Resources Center; YMCA in Princeton, The Glenbow Museum, Calgary, Alberta; The "Nurturing Ourselves" Women's Health Conference in Fredericton, New Brunswick, the University of South Alabama, and SHARE, Self-help for Women with Breast and Ovarian Cancer, New York City. Weekend Writing Retreats at the Mt. Calvary Retreat Center in Santa Barbara, Ca; The Shenandoah Crossing Resort in Northern Virginia, and Green Mountain at Fox Run, Vermont.
- 1992-1999 Antioch Writers' Workshop Faculty,** annual Intensive Workshop in Memoir.

Patient Advocacy

- 2005-2007 Website owner and developer, AdvancedBC.org** a resource for people living with metastatic breast cancer.
- 2007 Honored for "significant and sustained contributions to the fight against cancer,"** American Association for Cancer Research Annual Meeting, Los Angeles, 2007.
- 2005-2007 Patient Advocate, Center of Excellence (COE) *Studies Directed Toward the Eradication of Brain Metastases of Breast Cancer*,** involving more than 20 scientists, physicians and advocates, funded for 5 years by the Department of Defense Congressionally Directed Medical Research Programs. This COE is directed by Dr. Pat Steeg, Chief, Women's Cancers Section, Laboratory of Molecular Pharmacology and Director, Molecular Therapeutics Program Center for Cancer Research, National Cancer Institute. Helped to design and develop BRAINMETSBC.ORG a website for patients and families facing a diagnosis of brain or other central nervous system metastases, launched December 2007.

2005-2007 Member, Forum on Drug Discovery, Development and Translation, Institute of Medicine, the National Academies of Science. “The Drug Forum includes leaders from private sector sponsors of biomedical and clinical research; federal agencies sponsoring and regulating biomedical and clinical research; foundations; the academic community; consumers; and federal and private health plans. The Forum explores approaches to increasing the number, quality, and value of new drugs by making the drug development process faster, safer, more efficient, and more focused on the needs of patients. The range of issues the Forum addresses includes the full drug development pipeline—from drug discovery and regulatory approval to translation of research into clinical practice.”

2005-2007 Web-based Survey of Women with Advanced (Metastatic) Breast Cancer in conjunction with Living Beyond Breast Cancer, Ardsmore, PA. This in-depth needs assessment survey polled nearly 700 women living with metastatic breast cancer on their support, information and practical needs. A poster was presented at the 2005 San Antonio Breast Cancer Symposium, a White Paper “Silent Voices” was presented, summer 2006. The full report is available online at <http://www.lbbc.org/data/news/LBBCsilentvoices.pdf> Presented at APOS (American Society for Psychosocial Oncology) annual conference, Austin, TX, February 2007.

2005, 2006, 2007 Advocate Peer Reviewer, California Breast Cancer Research Program, Evaluated and rated research proposals in advance of a review of research proposals in meetings with scientists, clinicians and advocates for the purposes of recommending funding.

2001-2007 Patient Consultant with the FDA Cancer Drug Development Program

Patient Representative with the Oncologic Drugs Advisory Committee, ODAC

Patient Consultant responsibilities involve representing patient interests, experiences and needs in working along with FDA staff in the planning and conduct of clinical trials with pharmaceutical companies. As a Patient Representative, I have sat as a voting member of the Oncologic Drugs Advisory Committee, as well as serving on several other FDA advisory committees. I have participated in a monthly FDA training course offered by teleconference, and have drafted a brochure for new Patient Representatives.

2004 Member, Committee on Alternative Funding Strategies for DOD's Peer Reviewed Medical Research Programs, Institute of Medicine, the National Academies.

Report Published September 8, 2004: *Strategies to Leverage Research Funding: Guiding DOD's Peer Reviewed Medical Research Programs*, available at www.iom.edu/report.asp?id=22155

2004-2007 Member, Advisory Board. RegistHER Study, Genentech.

RegistHER is a prospective observational cohort study that will follow metastatic breast cancer patients with HER2+ breast cancer from the time of their metastatic diagnosis for the rest of their lives, tracking patterns of clinical practice and response to treatments. I am the only consumer member of this advisory board.

2003-2006 Member, Development committee for the LEADGradsOnline.org website a web-based resource for the 1,100 graduates of NBCC's science training course for advocates, Project LEAD, as well as LEADers, a mailing list.

2003-2007 Consumer Peer Reviewer for the Cochrane Collaboration

Participation as a Peer Consumer Reviewer for the Cochrane Breast Cancer Group in the review of protocols and preparation of new Cochrane Reviews.

2003 Commentator, California Breast Cancer Research Program

After meeting with Advisory Board and reviewing data from the California Cancer Registry and related literature on disparities in breast cancer care, wrote a detailed “white paper,” entitled *Treatment and Outcomes For High-risk and Metastatic Breast Cancer in California: An Inquiry into Disparities and Research Needs*. This white paper was presented at a meeting of the advisory board for the California Breast Cancer Research Program, and is available online at www.cbcrcp.org/publications/whitepapers/Mayer

1994-2005 Breast Cancer Discussion List (ListServ) www.bclist.org

Nine years of ongoing daily participation in an online Internet discussion group formed for a general discussion of breast cancer related issues with several hundred members from the United States,

Canada, the U.K. and many other countries around the world. E-mail sharing of evidence-based information and emotional support to newly diagnosed patients, and to women and their families who are dealing with advanced breast cancer. This work formed the basis of my book, *Advanced Breast Cancer*, and continues today, which involves my keeping up with clinical research in the field, attending medical and advocacy conferences, and translating complex medical information for patients to use in making informed, evidence-based treatment decisions. With the list owner, Dr. Jon Church, I prepared a study of usage patterns, perceived usefulness and attitudes of participants in this mailing list, which was presented as a poster at the San Antonio Breast Cancer Symposium.

1999-2007 BCMETS Discussion List (ListServ) for Metastatic Breast Cancer www.bcmets.org

Daily participation in this mailing list dedicated specifically to the discussion of advanced breast cancer, consisting of about five hundred patients and family members dealing with metastatic disease and related treatment and support issues. See description of the Breast-Cancer Mailing List above.

1999-2007 PAIR (Patient Advocates in Research) Discussion list

This invited mailing list is comprised of patient advocates who have a specific interest in cancer research and related issues.

1992-2007 Advocacy efforts on behalf of cancer organizations

National Breast Cancer Coalition, Y-ME, NABCO, SHARE, American Cancer Society, Living Beyond Breast Cancer, Young Survival Coalition, Breast Cancer Action and numerous other regional and local support organizations. Consultation and presentations at many breast cancer support groups and organizations on the topic of breast cancer survivorship, advanced breast cancer, support groups, researching breast cancer on the Internet, writing as a way of healing, updates on current breast cancer research, and medical conference reports, etc. (See Speaking Engagements)

2000 Recipient of Advocacy Award, National Breast Cancer Coalition

This recognition is presented to three women each year for their work as breast cancer advocates.

Publications: Books

Night Studio: A Memoir of Philip Guston by His Daughter

Alfred A. Knopf, 1988; Penguin, Thames & Hudson, 1990; DaCapo, 1997

About growing up in the New York art world of the 1950's. The New York Times called *Night Studio*, "a rich study in father-daughter relations...a memoir of depth and clarity."

Examining Myself: One Woman's Story of Breast Cancer Treatment and Recovery

Faber & Faber, 1993, 1994

A memoir of my own Stage II breast cancer diagnosis in April, 1989, and the mastectomy, chemotherapy and reconstruction that followed, as well as my emotional and physical recovery. Linda Ellerbee called it, "The very best book anybody has ever written about what it is like to have breast cancer." Amy Langer, Executive Director, NABCO National Alliance of Breast Cancer Organizations said: "*Examining Myself* is required reading for the woman who has taken the bold step of confronting her breast cancer head on and permitting it to reach her heart and soul."

Advanced Breast Cancer: A Guide to Living with Metastatic Disease, 2nd Edition

Patient-Centered Guides, O'Reilly & Associates, 1997, 1998

The only patient guide for the underserved patient population who live with metastatic breast cancer. Through solid information on treatments, side-effects and symptoms, as well as emotional coping, this book incorporates the experiences of some 35 patients and family members from diagnosis of first recurrence through hospice care. Dr. David Spiegel, Stanford University, author of *Living Beyond Limits*, called it "An excellent book....If knowledge is power, this book will be good medicine." The Breast Cancer Action Newsletter wrote: "Musa Mayer has given us a gift that we have needed for a long, long time: an in-depth, truthful, personal and informative resource about metastatic breast cancer. I believe that this book will be as important to women with metastatic breast cancer as Dr. Susan Love's *Breast Book* is to newly diagnosed breast cancer warriors." A 45 minute companion video, *Holding Tight, Letting Go*, was released in 1998, featuring nine of the 35

patients interviewed for the book sharing their problems, challenges and experiences.

After Breast Cancer: Answers to the Questions You're Afraid to Ask

Patient-Centered Guides, O'Reilly & Associates, April 2003

This new book's focus is on helping women with breast cancer cope with their uncertainty and fear of recurrence during the months and years after treatment ends, through stories and advice from 40 women who have been there, and an accessible review of the scientific and statistical literature on long-term survival and follow-up testing. Alice Yaker, former Executive Director, SHARE: Self-Help for Women with Breast or Ovarian Cancer wrote: "This long-overdue book helps women acknowledge what has happened to them, their uncertainty about what might happen in the future, and their great need to 'live life well.' Musa is the quintessential advocate; we are indebted to her for her courage, honesty and guidance." Dr. Clifford Hudis, Chief, Breast Cancer Medical Service, Memorial Sloan-Kettering Cancer Center, said, "This book provides accurate and helpful information for people who are worried." Bill Buchholz MD, Oncologist and Author of "Live Longer, Live Larger" wrote: "After the intense treatments of adjuvant therapy patients are cast adrift on the lonely seas of uncertainty. Out of her own experiences and the research she has done, Musa Mayer provides an accurate and sensitive map to these waters. With this guide, patients are no longer alone and doctors can offer their continued support when the last treatment ends."

Publications: Articles

"A Patient Perspective on Brain Metastases in Breast Cancer," *Clinical Cancer Research*, 13(6) March 15, 2007, pp. 1623-4.

"Loaded Language: Weighing in on War and Other Cancer Metaphors," with Gwen Darien, *CR Magazine*, Issue 1, Spring, 2006

"Listen to All the Voices: An Advocate's Perspective on Early Access to Investigational Therapies," *Clinical Trials*, 2006, 3, 149-153.

"When Clinical Trials are Compromised: A Perspective from a Patient Advocate." *PLoS Medicine*, November 2005, 2(11):e358 (Also published in *Cancer World*, March-April 2006)

"From Access to Evidence: An Advocate's Journey" *Journal of Clinical Oncology*, Vol 21, No 20 (October 15), 2003: pp 3881-3884

"Impressions from the 26th San Antonio Breast Cancer Symposium"

"Let's get real: Genomic models for prognosis, prediction, and treatment"

"Mining the Past to Predict the Future: Is It Possible?"

Breast Cancer Action Newsletter, February/March 2004 www.bcaction.org

Also on *SusanLoveMD.org*

"Follow-up Testing: Fears, Facts and Fallacies"

Carol Franc Buck Breast Cancer Center Newsletter, UCSF Comprehensive Cancer Center, Winter 2003

Features for *MAMM Magazine: Women, Cancer and Community* www.mamm.com

"Holding Tight, Letting Go," book excerpt, October 1997

"Lost and found," review of the first World Conference on Breast Cancer, Dec/Jan 1998

"Delayed diagnosis: Rage against the machine," Oct/Nov 1998

"Getting the bad news," Feb/March 1999

"Mind games: Weighing conflicting medical opinions," April 1999

"You're not alone: Finding the right support group," May 1999

(reprinted in *MAMM's Guide for the Newly Diagnosed*, 2000)

"Finally finding release: Confessions of a New Age seeker," June 1999

"Advocacy without borders," World Conference on Breast Cancer Advocacy, July/August 1999

"Writing your way to health," April 2000

"Breast cancer during pregnancy," May 2000

Musa Mayer – CV 2007

“Pregnancy after breast cancer,” June 2000
 “A survivor’s circular journey,” September 2000
 “Tales of life and living: Three videotapes dealing with advanced cancer,” February, 2001
 “The shock of recurrence,” Special issue on Advanced Breast Cancer, May 2001
 “Rethinking ‘Cure,’” March 2001
 “On the Death of Friends,” January 2002

 “BRCA1 and BRCA2 genetic mutations and breast cancer risk among Ashkenazi Jewish women,”
 Women’s American ORT, Jewish Women’s Magazine
 “Report on the 25th San Antonio Breast Cancer Symposium 2001” Project LEAD Newsletter
 “Report from San Antonio,” Breast Cancer Action Newsletter, 2001,2002, 2003
 “San Antonio Breast Cancer Symposium,” Living Beyond Breast Cancer Newsletter, 2001
 “San Antonio Report,” Alamo Breast Cancer Alliance, 2001, 2002
 “San Antonio Breast Cancer Symposium,” CancerLynx.org 2001, 2002
 ...Other articles too numerous to list in newsletters, newspapers and periodicals.

Speaking engagements:

“After Breast Cancer: Answers to the Questions You’re Afraid to Ask” 2002-2006 presentations

- Plenary Address to the World Conference on Breast Cancer, Victoria, BC 2002
- Keynote at Madison Breast Cancer Recovery Foundation, Madison, WI 2003
- Keynote at Hamilton Breast Cancer Program Conference, Hamilton, Ontario, 2003
- Keynote at

Presentations at Mid-Hudson Breast Cancer Options; Cumberland Valley Breast Cancer Awareness; Breast Cancer Coalition of Rochester; Ithaca Breast Cancer Alliance; Breast Cancer Action, San Francisco; Austin Breast Cancer Coalition; Rhode Island Breast Cancer Coalition, Providence; Living Beyond Breast Cancer, Young Survivors Group, Philadelphia; Young Survival Coalition Annual Conference, Philadelphia; Willow Breast Cancer Support & Resource Services in Windsor, Ontario.

“Living with Advanced Breast Cancer” 1998-2004

Wellness Community, Philadelphia; Mautner Conference on Lesbians and Cancer; Austin Breast Cancer Resource Center; Rochester Breast Cancer Coalition; ACS Nurses Training Day, Utica; SHARE; two World Conferences on Breast Cancer; MAMM Magazine WebCasts 2000, 2001; WebMD WebCasts 2000-2004; Many radio interview/call-ins

“Report back from the San Antonio Breast Cancer Symposium”

SHARE: Self-Help for Women with Breast and Ovarian Cancer, New York, 2000, 2001, 2002, 2003, 2006

“Challenges and Choices: A Survivor Talks about Life After Breast Cancer”

North Carolina Breast Cancer Coalition, Southwest Oklahoma Breast Cancer Alliance, Tulsa, 2001

Presenter and Consumer/Advocate Panelist, with Eric Winer (Dana Farber),

Metastatic Breast Cancer Symposium, Boston, April 2002
 Massachusetts Breast Cancer Research Program Annual Meeting

Co-Presenter, “Proteomics, A New Approach to Understanding Breast Cancer,” NBCC Annual Advocacy Training Conference, May 2003

Panelist, Plenary Session, The Role of the FDA in the 21st Century: Safety, Science and Speed, NBCC Annual Advocacy Training Conference, May 2003

Panelist, UCSF Symposium on Ethical Considerations in Genetics, San Francisco, April, 2003

Chaired, Institute of Medicine Panel on “Mammography and Beyond,” SHARE: Self-Help for Women with Breast and Ovarian Cancer, NYC, 2002

“Reach to Recovery: Advanced Breast Cancer, development and taping of training modules,” American Cancer Society, Atlanta 2001

Presentation, Breast Cancer Drug Development workshop
NBCC Annual Advocacy Training Conference, 2002

“Can we individualize the treatment of patients with breast cancer based on genomic profiling?”
“New Approaches to Breast Cancer Metastasis”

Panelist representing advocacy perspective, **Era of Hope**, The Department of Defense Breast Cancer Research Program Conference, Orlando, 2002

Consumer panelist, Case Presentation on Advanced Breast Cancer
San Antonio Breast Cancer Symposium, San Antonio, December, 2002

Teleconference with Dr. Eric Winer (Dana Farber) on Advanced Breast Cancer, NABCO an BreastCancer.org, September, 2003

“Treatment and Outcomes for High-risk and Metastatic Breast Cancer in California: An Inquiry into Disparities and Research Needs,” presentation of white paper for the California Breast Cancer Research Program, November 2003 <http://www.cbcpr.org/publications/papers/Mayer/index.php>

“Phase III Clinical Trials: Are we answering the important questions?”

“Phase II Clinical Trials: When do we know enough about safety and efficacy?”

“Navigating to Knowledge: Keeping Current with Breast Cancer Research”

Faculty presentations for Clinical Trials Project LEAD training, December 2003

Industry Roundtable Respondent, Early Access to Investigational Treatments, National Coalition for Cancer Survivorship, March 2004

Presentation and Discussion, “Living with Metastatic Breast Cancer,” with David Mintzer, MD at the Wellness Community, Philadelphia, March 2004

Keynote Speaker, “Advanced Breast Cancer: Tools for the Journey,” Rochester Breast Cancer Coalition, March 2004.

Panelist, Plenary Session, “Latest Controversies and Complexities and the Role of the Breast Cancer Advocate,” NBCC Annual Advocacy Training Conference, May 2004.

Workshop Presenter, “Clinical Trials: Are We Asking the Right Questions?” NBCC Annual Advocacy Training Conference, May 2004.

Webcast for SusanLoveMD.org with Dr. Joyce O’Shaughnessy, Dr. Susan Love, “Advanced Breast Cancer: Beyond Hormones,” October, 2004, transcript at http://susanlovemd.com/chat_frames_040914.html

Keynote speaker, “Searching in the Dark,” Emerging Topics in Breast Cancer and the Environment Research, Conference organized by the National Institute for Environmental Health Sciences (NIEHS), Princeton, NJ, November, 2004.

Speaker, “Metastatic Breast Cancer: Quality of Life,” Webchat for SusanLoveMD.com, with panelists Drs. Susan Love, Debu Tripathy, and Hope Rugo. San Antonio Breast Cancer Symposium, December, 2004.

Speaker, “Clinical Trials 101,” presentation to SHARE and JALBCA (Judges and Lawyers Breast Cancer Alert), March, 2005.

Fresh Air, Half Hour Interview with Terry Gross WHYY, broadcast on NPR affiliates.

Speaker, “Treating the Whole Woman,” One and a half hour panel discussion at the annual conference of the American Society for Breast Disease, Las Vegas, with Debu Tripathy and Gwen Darien.

- Speaker, FDA Advisory Committee New Member Training, April 2005.**
- Speaker, “Ethical and Clinical Dilemmas Resulting from the Early Closure of Recent Clinical Trials in Breast Cancer.”** Educational Session, American Society of Clinical Oncology (ASCO) annual meeting, Orlando, presented on May 13, 14, 2005.
- Plenary Speaker, “Breast Cancer Research: Your Tax Dollars—Who Benefits?”** National Breast Cancer Coalition Annual Advocacy Training Conference, May 2005.
- Speaker, “Post-Marketing Surveillance,”** NBCC Annual Conference, workshop with Susan Sacks, Roche, and Vicki Goodman, FDA, May 2005.
- Speaker, “Gene Panels: Promises, Progress and Limitations,”** with Joanne Zujewski, NBCC Annual Conference, May 2005.
- Plenary Speaker, “Forum on Making/Influencing Public Policy,”** Society for Clinical Trials annual meeting, Portland, Oregon, May 2005.
- Speaker, “Genomics, Proteomics and Clinical Trials,”** Society for Clinical Trials annual meeting, Portland, Oregon, May 2005.
- Speaker, “Best Practices for Patient Advocates”** Clinical Trials Summit, September 2005.
- Speaker, “Enhancing Drug Safety in the 21st Century,”** American Academy of Pharmaceutical Physicians Annual Meeting, Philadelphia, November 2005.
- Keynote Speaker, “Issues After Breast Cancer,”** and **“Metastatic Breast Cancer: Tools for the Journey.”** Susan G. Komen Conference, Portland, Oregon, March, 2006.
- Plenary Speaker, “Breast Cancer in the 21st Century: Hope or Hype?”** National Breast Cancer Coalition Annual Advocacy Training Conference, April 2006.
- Plenary Speaker, “Potential New Frameworks and Approaches to Better Assess and Communicate Benefit/Risk,”** PhRMA Town Hall Meeting, Washington, DC, May 2006.
- Panel Speaker, “Barriers to Clinical Trials Enrollment: the Patient Perspective,”** World Cancer Congress, Washington, DC. July 2006.
- Speaker, “Advanced Breast Cancer: Tools for the Journey,”** Y-ME Share-Ring Network Teleconference, September 2006.
- Presenter, Workshop: “Understanding Evidence-Based Healthcare: A Foundation for Action,”** Cochrane Colloquium, October 2006.
- Discussion Leader, event to launch The Wellness Community, “Patient-Active Guide: Advanced Breast Cancer,”** October 2006.
- Presentation of “Silent Voices: Women with metastatic breast cancer share their needs and preferences for information, support and practical resources,”** survey results at the American Psychosocial Oncology Symposium (APOS), March, 2007.
- Presentation of Silent Voices survey results to staff, volunteers and clients of SHARE: Self-Help for Women with Breast and Ovarian Cancer,** April 2007.
- Plenary Speaker, “Evidence-Based Health Care: What Would it Mean for Patients?”** National Breast Cancer Coalition Annual Conference, April 2007
- Presentation, “What do we really need to know? An advocate reflects on early access, safety, and the search for best evidence,”** Cancer Prevention and Control Colloquia Series, National Cancer Institute, June 2007.
- Interview, “The Quiet War: Living With Advanced Breast Cancer,”** Affinity Films, CD-ROM, released June 2007.
- Presenter, Discussion for Women with Metastatic Breast Cancer,** for Breast Cancer Options, Benedictine Hospital, Kingston, New York, July 2007.
- Plenary Speaker, “New Directions in Breast Cancer Treatment,”** California Breast Cancer Research Program (CBCRP) Symposium, Los Angeles, CA September 7-8, 2007